

NORTH
JERSEY
COMMUNITY
RESEARCH
INITIATIVE

All About
Clinical HIV Trials
in Northern New Jersey

NORTH JERSEY COMMUNITY RESEARCH INITIATIVE (NJCRI)

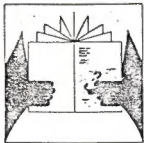
A subsidiary of

NORTH JERSEY AIDS ALLIANCE, INC.

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Getting the best treatments as quickly as possible to the community...

ABOUT CLINICAL TRIALS AND HIV**WHAT IS A CLINICAL TRIAL?**

A clinical trial is a study with patients to evaluate a new drug or treatment. Each study is designed to find new and better ways to help patients. The search for good treatments begins with research in laboratory and animal studies. The best results of that research are tried in patient studies. With a new drug there may be risks as well as benefits. Only patients who wish to, take part in clinical trials.

WHAT IS HIV?

HIV stands for "Human immuno-deficiency virus" - the virus that is believed to cause AIDS (acquired immune deficiency syndrome). In northern New Jersey over 50,000 people are believed to be infected with HIV. Some display no illness. Others have symptoms that range from minor ones to full-blown AIDS. NJCRI wishes to offer clinical trials to the full range of people with HIV.

WHAT DRUGS EXIST FOR CLINICAL HIV TRIALS?

Over 100 different AIDS-related drugs have shown promise in the laboratory. However, lack of funds and personnel has prevented the government from testing them. Other drugs need additional testing to be sure they are safe and effective. Aerosol pentamidine is an example of a drug that is undergoing clinical trials.

ARE THERE CLINICAL TRIALS IN NORTHERN NEW JERSEY?

Local hospitals occasionally hold clinical trials, but there is no group in our area whose main task is to conduct HIV trials for adults. The nearest sites are in Manhattan and central New Jersey. For most people, these places are inaccessible. We established NJCRI to make trials available in our local communities.

QUESTIONS TO ASK ABOUT A CLINICAL TRIAL

- * What does the trial involve? What tests and treatments?
 - * What is likely to happen in my case with, or without, this new treatment?
 - * How could the trial affect my daily life?
 - * What side effects could I expect?
 - * What are my other choices?
 - * What type of long-term follow-up care is part of the trial?
 - * If I am harmed as a result of the research, what treatment would I be entitled to.
 - * How long will the trial last?
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ABOUT NJCRI

WHAT DO WE MEAN BY "COMMUNITY"?

We work and live in northern New Jersey. We include people with AIDS and those at risk. We are blacks, whites, Hispanics - women and men. We support the rights of drug users, children, and gays.

WHY ARE WE COMMUNITY-BASED?

Most research will continue to be carried out by government and large institutions. But a community-based group offers local doctors. Also, a community group can meet local needs in a way a national program cannot.

ARE WE THE ONLY COMMUNITY-BASED RESEARCH GROUP?

No. Community Research Initiative, of New York City, started this approach in 1987. They are operating various trials, including one for aerosol pentamidine. Similar groups exist in other states.

IS RESEARCH IMPORTANT?

Yes. Only through research can we find better drugs. It is important to learn what treatments are safe and effective so they can be made available as soon as possible.



WHAT DO WE MEAN BY "INITIATIVE"?

We are doctors, professionals, volunteers, and people with HIV who are taking the initiative to work together. We believe that through responsible research we can find solutions to the epidemic.

HOW ARE DOCTORS HELPING?

Doctors are on our committees. They also are ready to administer promising, new treatments. Over 40 doctors are helping us.

WHO ELSE IS HELPING?

Many groups are helping, including People with AIDS Coalition of New Jersey, Coalition on AIDS in Passaic County, Community Foundation of New Jersey, Community Research Initiative of New York, and hospitals.

OUR GOALS

- * OFFER PROMISING, INVESTIGATIONAL TREATMENTS IN THE COMMUNITY TO ALL AFFECTED GROUPS.
 - * SPEED THE PROGRESS OF AIDS RESEARCH.
 - * HALT, AS SOON AS POSSIBLE, PROGRESSION TO FULL-BLOWN AIDS IN THOSE AT RISK.
 - * TREAT OPPORTUNISTIC INFECTIONS.
 - * SEEK TO FIND A CURE.
-

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ABOUT JOINING A TRIAL



WHAT IS A CONSENT FORM?

Before entering a trial you are given a consent form to read and consider carefully. The form explains the purpose and procedures of the trial, including possible risks and benefits. After asking any questions you have, you sign the form if you agree to take part. Of course, you may also refuse.

WHAT IS IT LIKE TO BE IN A TRIAL?

When you join a trial, you may receive an experimental treatment. You will be watched closely, and data on your condition will be recorded. You may receive more examinations and tests than normal. Doctors, nurses, social workers, and others may help care for you.

CAN I LEAVE A TRIAL AT ANY TIME?

Yes. Just as you can refuse to join a trial, you may leave a trial at any time. Refusing to join a study or leaving a study involves no penalty or loss of benefits to which you would otherwise be entitled.

WHAT PROTECTION DO I HAVE?

All trials are approved and monitored by our Institutional Review Board which protects the rights and welfare of volunteers. The board includes doctors, non-doctors, and a person with AIDS.

WHAT DOES A TRIAL COST?

Generally, there is no charge for the experimental drug, the tests that are used to evaluate the study, or the support services. You do pay for "routine care" costs.

WHAT ABOUT CONFIDENTIALITY?

You will be assigned an I.D. number which will be used, instead of your name, on your medical records. The fact that you are in the study will be kept as confidential as possible within the law.

WHY JOIN A TRIAL?

Usually you hope for benefits for yourself. You may hope for a cure of the disease, a longer time to live, a way to feel better. You may want to contribute to a research effort to help others. You may also wish to be among the first to receive promising, new treatments.

WHAT CAN I DO TO FIND OUT MORE?

Consult a doctor. Both private and clinic doctors who are NJCRI Participating Physicians know about our plans. If your doctor is not an NJCRI Participating Physician, ask him or her to contact us.

NORTH JERSEY AIDS ALLIANCE, INC. - Bob Sproul, President

NORTH JERSEY COMMUNITY RESEARCH INITIATIVE:

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